

CHAPTER 4

CASE STUDIES

The JLS field researchers prepared case studies on six *Jackson Class* members whom they were able to visit five times in the community over a period of *four* years. The first visit (T1) was typically made about four months after the client's initial move from the institution and the second (T2) at around the end of the first year. We conducted annual visits thereafter. The fifth and last visit (T₅) was made at the end of the client's fourth year of living in the community. The case studies are in our interviewers' own words and have been only minimally edited. They reflect the diversity of the *Jackson Class* population and the individuality of its members. They also show that our interviewers were able to gain considerable insight into the lives of the people they visited.

Andy

Andy, a middle-aged man, moved from Ft. Stanton into a medium-sized city in 1993 at 47 years of age. When he first moved from the state hospital, he shared his living space with another fellow with whom he did not get along. They fought and so were separated with Andy then being moved into his own apartment. Since that time, Andy has uniquely lived with no roommates and has had quite an independent life.

*Andy is a loner with a
fierce determination to be
independent*

The most remarkable aspect of Andy's placement in the community at T1 was the degree to which he has been left alone. He apparently had had troubles with peers at Ft. Stanton as well. In the first year, he got a part-time job and later a regular job doing maintenance work at county rest areas off the interstate. Andy loved to work and loved being left alone. Staff would come to his apartment to spend the night, help the client shop for food, prepare meals, provide medications, and escort him to medical appointments, but other than these specific times, Andy would be alone. He spent his time walking all over town, sometimes taking buses, getting to work by himself, doing light shopping, and occasionally eating at restaurants. Andy stated that he is completely self-sufficient, hardly acknowledging staff help or presence except for one woman whom he likes who prepares meals.

Andy appeared to be a loner. His social activities in the first year were limited pretty much to church. He gardened a little patch outside his apartment and was proud to show off his work. His relationship with his family (who lived in a nearby community) was an important part of his life. His father and brother would visit him regularly at his apartment and he in turn would visit his family weekly.

By our T₂ visit, Andy's social life had begun to change. He stated that he now went to agency functions and had a lot of friends at work and at the agency. His family contact appeared to lessen; he no longer reported any family visiting him at his apartment while his visits to the family home declined in number. His most important focus appeared to be his

***Work was crucial to
Andy's self-image early on
in the community.***

work. He got up at 3:30 a.m. to be ready for a 6:00 arrival of his transport to work at the rest areas. When greeting the interviewer he was dressed in immaculate work clothes and his home was perfectly clean. Going to work was very important to him and *doing* good work even more. His ability and independence in work were crucial to his self-image, and were the basis of his comparison with his life at Ft. Stanton. His comments on his bosses corresponded to his happiness at work, and at this point he was happy with his boss. He mentioned enough about life at Ft. Stanton to signal to the interviewer that his relationships with authority figures were difficult. His own view of his independence was somewhat belied by the fact that residential staff still did major food shopping, paid his bills, prepared meals ahead and put pre-cooked food into containers easy for him to use.

***Socially, Andy had a
rough second year.***

The year before our T3 visit was difficult for Andy, particularly with regard to his work and social life. At the time of our interview he had lost his job because of fighting with a peer. He was very bitter about this, stating that it was unfair, blaming the peers he worked with for laziness, and blaming his boss for favoring them and not standing up for a strong work ethic. (His comments came across as somewhat paranoid.) At the same time, he noted that his family seldom visited him and that he didn't visit them at the family home any longer. Moreover, his relationship with staff (they were the same staff as in the prior year) seemed to sour, except for the woman who helped him with shopping and food preparation. On a more positive note, he now was able to visit the doctor on his own.

***Year 3 brought a new
residential provider,
higher priority on social
interaction, and a new job.***

Andy's life in the community improved during the next year. At T₄ a new agency had taken over his supervision, and had made social interaction a top priority on his ISP. Andy reported that he once again had friends at the agency center. He took part in agency activities more often, even going to dances. This didn't come at the expense of his independence - he was more independent than ever. The new agency sent staff to his apartment for only two hours a day, and none on weekends. Staff did not "sleep over." Though still helping with shopping, bills, food preparation, laundry and medications, the agency clearly acceded to Andy's wishes and gave him "more room," and Andy was happier with this new arrangement.

Most importantly, Andy got a new job - still maintenance/janitorial - but he said he liked his co-workers and bosses and felt he was being paid properly (whereas before he felt the agency wasn't paying him enough). He was again visiting his family weekly, and they were visiting him at his apartment, as well.

***Recently, Andy has begun
to find a balance among
the many facets of his life.***

During the final JLS visit (T₅) Andy reported that he has friends "everywhere." He was clearly happier than ever before since entering the community. Interestingly, he noted that he was now holding two jobs and liking both, but was tired and wanted more rest. He was getting "tired of cleaning up after people." For the first time, Andy, who was clearly more socially engaged and reported having more friends, seemed to want more balance in his life, a departure from the work need of previous years.

Andy also reported that agency staff trusted him more, and that his landlord "fixes things" now. Staff still take him to the bank, shopping, and to medical and dental appointments. But now he recognizes this as being helped and not being intruded upon. He reported being "always" happy and was obviously content with the balance of services and independence that had evolved for him.

In summary, Andy has matured during his four years in the community. His initial happiness and sense of independence are more modulated and realistic. He exhibits pride and self-esteem without the paranoia he showed earlier. He has learned to be with people in necessary ways without so much resentment and uncertainty. He is without doubt the most independent of the *Jackson* movers this interviewer has encountered during the four years of the study.

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'Ben"

Ben's first days in the community offered much freedom and choice - perhaps too much.

He appreciated agency staff who helped him learn sign language.

*Ben helped to choose his
----- job.*

Ben is an early middle-aged deaf man who moved out of Los Lunas in early 1993. He was moved into a small, rather old apartment near a busy downtown intersection and had one roommate. The apartment was not set up for a deaf resident. It had no lights to signal the doorbell, smoke alarm, someone wishing access to the bathroom, or a TTY telephone device. The furniture was marginal and personal space cramped. Ben was allowed to drink beer and to keep his own cash, allowing him to walk across the street and buy his own. An alcoholic neighbor had a key to the apartment, degrading the safety and security of all who lived there.

Ben was, however, given the opportunity to begin to learn sign language. (He apparently had been **taught** little or none at the state hospital.) He was given four hours a week of signing instruction, and agency staff (one in particular) were attempting to learn signing as well. Ben showed great joy in having someone attempt to communicate with him and show concern and interest in what he wanted to express.

Ben liked his roommate, but often wanted to be alone. His access to the community was quite good, as he could walk to the city center or take buses, which stopped nearly at his front door. He often went on outings with staff and peers, going to square dances and fiestas, to play basketball and tennis, and to go rafting. Still, he had no visits from his very large family (which included 17 siblings).

At the time of our T, visit he had picked his own work with the help of staff, choosing janitorial work and doing well with the aid of a job coach. Although he earned and kept his own money he was observed begging, presumably to buy beer at the 7-11 across the street.

During the time between our initial visit and the end of his first year in the community, Ben's adjustment appeared positive. He continued to receive signing training. His ability and that of the staff were still quite minimal, but all were making a real effort to communicate and Ben clearly appreciated it. The residence had not changed, but accommodations for deafness had been made including a flashing smoke alarm and doorbell, and a TTY device.

By this point (our T₂ visit), Ben expressed less desire to be alone yet also showed anger more often, possibly indicating a growing sense of comfort in his new home. Importantly, staff completely cut Ben's alcohol consumption, giving him alcohol-free beer at times and monitoring, as far as possible, his trips to the store in that regard.

Socially, this period was one of considerable change. Ben began participating in outings such as picnics and in community activities including an advocacy group with other deaf individuals primarily from the NM School for the Deaf. In the area of work, Ben had become dissatisfied with his job and chose to change, getting a job at a local car dealership and wanting to enlarge his duties beyond just mopping.

Moving to a new home and events during year 2 in the community were traumatic, and receiving less attention didn't help.

Our T₃ visit revealed very changed circumstances during Ben's second year. He had moved out of his small apartment into a larger home, but the house was poorly maintained, and the staff-client ratio had increased from 2:1 to 3:1. Staff felt Ben was receiving less service, particularly regarding signing training, and fewer staff members could attempt signing at all. Ben clearly felt less understood and appeared withdrawn. He signed that he felt no fear, anger, or sadness when asked, but his affect belied this. Staff inferred something terrible had happened, but would not explicitly state what that was. (Later interviews would bring out that a housemate had sexually assaulted Ben.)

Outside the home social activity had waned during this time and Ben was involved only with Special Olympics. He was less satisfied at work than at the start of his community placement, perhaps an outgrowth of his deteriorating home life.

Year 3 brought a positive change - a dramatically improved living situation.

Ben's situation dramatically improved during his third year in nearly all areas of his life. He now lived with a professional who had twenty years of experience with developmentally disabled adults and children. His living situation resembled adult foster care. The home (belonging to the primary care giver) was brand new, with all new furniture, and tastefully decorated. Ben had his own room, with a new TV, new furniture, new clothes, and a small deck outside his bedroom. His personal space was excellent, and he was visibly proud when showing his room and possessions. Ben had shared the house for short periods of time with another deaf man, an adolescent, and got along with him well. (The house is a respite home for the adolescent.)

Ben's social life and choice of activities were greatly enhanced. He was now attending art classes, horseback-riding therapy, and going to parties, barbecues, movies, mall and shopping outings. He was clearly happier and excited about his life choices. He was happier at work, liked getting paid and using his money for activities. He had a girlfriend, whom he met at the new agency's social/community group. He said he was no longer afraid and importantly was no longer having nightmares as he was before the latest move. He went on daily walks by himself, did yard work, and had friends over to visit. The living climate was one of safety, caring and respect.

During the fourth year, Ben's life continued along the same positive course. He still lives in the same home, although now has one full-time

housemate. Still he is given a great deal of 1:1 time with the primary care giver. Support staff come into the home to take him on outings and he likes them all. The primary staff person is very knowledgeable about his needs and encourages choices. Ben is healthy and appears quite content. He continues to maintain a relationship with the same girlfriend, goes to an art club by himself, goes fishing with others, and continues to hold the same job, now without a job coach. There is no indication of drinking, although he goes to work and into the community on his own. He feels safe in his home and exhibits, now, a strong sense of ownership and pride in what is his, whereas in earlier years he might easily have been victimized or "given" his things away.

Overall, Ben's life, surroundings, ability to communicate, socialization, activities, relationships and work life have improved dramatically in the past two years. Everything about his life - choices, safety, and inclusion - has moved from relatively poor to the best I have seen in the years of visiting *Jackson* clients. The ability of his current agency to set Ben up in a unique "fostering" environment with agency supports has made this placement incredibly successful, enabling a dramatic turnaround to Ben's benefit.

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"Jeff"

Jeff is a young man in his thirties with CP. He walks independently and is very expressive verbally though frequently difficult to understand. Jeff moved out of Fort Stanton and back to his home community in 1993. He has a very supportive family who live nearby; visits to and from them increased after his move. As Jeff had been living in an "Independent Living" cottage at Ft. Stanton, he was already managing considerable responsibilities regarding his personal care, household management, and work life before his move. This seems to have made his adjustment to community life quite smooth in many areas.

Jeff wants and expects others to treat him as "normal" and has had difficulty accepting his disability.

The central issue in Jeff's life, as observed through this four year period, is his own difficulty accepting his disability and the many frustrations he experiences as others try to understand his speech or treat him as though *he is mentally* retarded. Consistently, he has stated his preference *not* to associate with persons with developmental disabilities. (His own IQ apparently borders on normal.) The two agencies working with him in the past four years have respected that request. One of the most important things to Jeff has always been for staff and others to treat him as a peer or a friend, rather than as a "client."

Though it seemed on the first visit that some type of counseling or psychotherapy would be advisable for Jeff, neither he nor either agency has sought any service of this kind. Staff members have continued to work on these issues with them, and four years after his move they have a much greater understanding of his issues and associated behaviors, and make ongoing efforts to support him in addressing them.

Jeff has greatly appreciated living in a regular house in a nice neighborhood. His first 2 1/2 years since moving were spent in his previous home community, near his family. He enjoyed the freedom and responsibility of setting up his own home, choosing furniture, and

Jeff initiated a move to a larger community where he would have more opportunity.

deciding where things should go, as well as keeping his bedroom exactly as he wanted it. His housemates have been other young men who were also very independent and capable. Jeff takes great pride in his home and enjoys offering visitors a cup of coffee.

In his second year, staff indicated Jeff had changed tremendously. They said he now acted like a "regular person" instead of a "Jackson person" (as Jeff had put it when he first moved into the community) who needed special treatment. Although he had eagerly wanted to return to this community, and the agency there was very supportive of his choices and needs, it wasn't long before he was dissatisfied with the lack of things to do or adequate job or college opportunities. His agency supported Jeff's wish to visit another city about two hours away to see if he might like to move there. The visits, agency interview and talks with his family eventually led to Jeff's move to the new city about 2 1/2 years ago. The move proved to be a good one in that Jeff has made new friends, has had two jobs he has really liked, and is very satisfied with the local agency.

When his agency decided Jeff should not live with a housemate, he had great difficulty accepting the fact

Jeff's first residence in the new city seemed an excellent one with two housemates. Unfortunately, Jeff became overly attached to one of his housemates, which became problematic. When this house burned down (no one was hurt) during the first year, staff decided Jeff should not live with this other housemate (or anyone else) until he had dealt with his difficulty in respecting others' personal boundaries. This resulted in Jeff's engaging in some violent outbursts and stopping eating. (Staff interpreted this as a suicide attempt.) He was hospitalized for some time before moving back into the community, this time to a small apartment where he lived with staff but no peers. At the final JLS visit, Jeff indicated he was lonely and unhappy living alone but he never talked about why he was living alone.

Recently, Jeff has begun to deal with the issues he had often blamed on others or his situation, and appears much happier.

In many respects, the last interview seemed to reflect the greatest reality. For years, Jeff had complained or indicated he wanted something different from what he had in his life. Staff in the first agency thought he would never be a happy, satisfied person, largely because he couldn't accept his disability. However, in this new town and agency, Jeff has begun to work on some of the issues that make him unhappy, together with staff who respect him enormously. Jeff still expresses his frustrations but appears to "own" them rather than blaming others or wanting to change his living situation.

Jeff has always had the skills and motivation to access community activities. He rides the bus and walks extensively. Early interviews indicate he often rode the bus around town by himself. In those days he was a "loner," partially because he didn't feel he fit in with a peer group. More recently, he has said he enjoys outings with others - baseball games, mall trips, a drama club - which may indicate a greater acceptance of both himself and others. Staff in both agencies have consistently respected and supported his choices and decisions regarding community involvement.

Jeff is a small, wiry man whose body is in almost constant movement from the CP. He has always had difficulty keeping weight on. Records

indicated staff thought this was due to the CP alone, but more recently Jeff has been observed to refuse to eat when he was not allowed to do what he wanted, to the point of needing to be hospitalized. This behavior is now understood to have been anorexic and suicidal, indicating deeper psychological issues than previously recognized. Apart from this, Jeff's physical health has always been reported to be excellent.

A large part of Jeff's frustration — as well as his satisfactions - have related to his work life. He has often tried to take college courses both to find an acceptable peer group and to learn to become a teacher. Neither goal has been attained, and both may be unrealistic, but Jeff has shown commendable determination to better his life. His CP and resulting lack of physical coordination have hampered success in several job settings. However, in the past two years he has worked as a mail sorter and distributor for a school administration *and as a* file clerk for his provider agency. Both jobs have brought him success and satisfaction, and reflect the effort the agency continues to make to support his ambitions. Jeff's sense of personal empowerment has clearly grown significantly through such experiences, and it would seem he has yet to reach the limit of his abilities and dreams.

"Rosa"

Rosa has lived happily in the home she moved to from the institution, and sees it as hers.

Rosa is a middle-aged woman who moved from Los Lunas 4 1/2 years ago and still lives in the original residence she moved to. Although her move was to the town where many of her siblings and relatives live, family visits have not increased, still occurring only once a year. Agency staff have frequently encouraged more contact. They have assisted Rosa in writing letters to family members and inviting them to parties and gatherings. Other social relationships have been encouraged, but as Rosa does not participate in a day program, her friendships are almost entirely with her housemates and staff. Over the years, these friendships have grown very solid and comfortable. Rosa is wary of new staff, but is very relaxed and trusting with long-term staff.

Rosa's home is a very comfortable but small three-bedroom house in a nice residential neighborhood. Originally, three residents were placed in the house, but after two years of problematic relationships with a third resident, now only two women share the house with staff. These two women have lived together for 4 1/2 years and are best friends. Because the women do not want a third housemate, the agency subsidizes their rent so that they can afford not to have an additional person.

This residential situation has been and is treated by agency as a long-term home. The residents have chosen colors to repaint the inside of the house, and they have planted and harvested a flower and vegetable garden for three years. Rosa's housemate has had a pet dog for three years, which Rosa now enjoys playing with. The house and yard are very well maintained.

From observation and reports, staff and residents make all major decisions together, including menus. The two women clearly know this is *their* home - that they are in charge and in control of what happens there.

Rosa's ability to gain access to the community has involved both assistive aids and personal changes.

This home is several miles from the town center and Rosa uses a wheelchair, so transportation has been a challenge. In her second year in the community a new collapsible wheelchair was purchased which made it possible for staff to take this woman and her wheelchair out into the community in staff cars. Rosa, however, loves to eat, and in her first years out of Los Lunas she gained considerable weight. This made it more difficult for staff to lift her in and out of cars. As these problems were recognized, she has been supported to be on a low-calorie diet and to wheel herself around the house independently. This regimen has contributed to increased strength, balance, and ability to care for herself, including dressing, brushing her teeth, feeding herself, carrying dishes to the sink, and helping with transfers to and from her bed and bath trolley. In her third year in the community, the agency purchased an accessible van for the women in this home, and community access has increased still further.

She has been helped to make noticeable improvements in personal functioning.

Before leaving Los Lunas, Rosa was usually excluded from group outings as she was the only resident in her cottage that used a wheelchair, and the cottage lacked an accessible van. Since the move, all interviews have indicated that outings are a favorite activity, and they are strongly supported by staff. Rosa goes out a lot - to eat nearly every day, grocery or clothes shopping at least weekly, to the movies weekly, to church every Sunday, to the zoo frequently. Moreover there are daily car rides to do errands and at least once a week a visit to a staff person's home.

Rosa is in generally good health apart from a tendency to develop hypothermia. This is monitored closely by staff and has not occurred in the past two years. Rosa is in diapers, which are changed every two hours, preventing hypothermia. In the past two years she has begun to be able to tell staff when she is wet and needs to be changed, and so she has gone onto a regular toileting schedule throughout the day which is proving somewhat successful. Records indicate she had never been toileted before. By staff report, Rosa has a very concerned doctor who follows her health closely.

Perhaps the greatest health issue Rosa faces is being overweight and enjoying food so much. In her first year, staff members were instructed to support and follow her choices. As a result, she gained a lot of weight. Gradually staff realized they needed to help her limit her food intake so that she could get around more easily, and so they could manage to transfer and lift her. As a result, Rosa now gets out into the community more, which "feeds" her in a different way and makes her very happy.

An early staff decision that she could not participate in a day program may be limiting Rosa's development.

Because Rosa uses a wheelchair and has the use of only one hand and arm, the agency decided she could not participate in a day program. They were unable to obtain a vocational assessment for Rosa when she first left the institution and apparently haven't tried since. Therefore, they designed a home-based program which includes weekly visits to physical, occupational and speech therapists, drying dishes, learning self-care skills, doing arts and crafts, stirring food and helping clean the house. Interviews reflect how social Rosa is and how much she enjoys contributing and participating in activities. It appears this is an area that needs further exploration. Rosa has not had to develop vocational skills,

Rosa is clearly more capable than her diagnosis in the institution indicated.

attitudes and behaviors in her past, but she clearly appears to have greater capabilities, intelligence and interests than previously known. Her Los Lunas records indicate "profound MR" but one conversation with Rosa today clearly negates that diagnosis. She is able to converse and joke in a quite sophisticated and abstract manner.

When she first moved out of Los Lunas. Rosa was considered to be "echolalic," as she mostly repeated whatever was said to her with a big smile. During the four years she has been in the community, her speech has become more and more appropriate, reflecting her opinions as well as her intelligence. Staff members are all taught not to answer questions for her (as was done in the past) but to give her plenty of time to state her opinions and choices. She now does this frequently, sometimes after repeating the question or suggested answers.

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"Dixie"

After living in Los Lunas for nearly 25 years - except for a difficult two-year stay in a companion home as a teenager - it is hardly surprising that Dixie (who is now 37 years old) was reluctant to move from the hospital and fought hard not to go. At the T₀ (institutional) visit she begged our interviewer to let her stay. She had to be told repeatedly that we had no power to make these decisions. When the interviewer attempted to point out the positive aspects of the move she sighed, stood up and left the interview.

Dixie's coping strategies have presented challenges for her staff.

Dixie has very little speech and relies mostly on a combination of gestures and signs to communicate. She has a history of aggression and of Munchausen Disorder - feigning illness to get attention. She presented a complicated picture - both very perceptive and emotionally conflicted - to our field researcher. Her emotional traumas and coping style have been the most challenging factors in her adjustment to life away from the institution. Dixie presents challenges that require very savvy staff. Her progress has been heavily dependent on their ability to provide a safe environment. She was clearly very comfortable in her Los Lunas environment, and particularly close to a number of staff. She had some fights with other residents, but she also identified some residents as friends. She had moderate contact with her family, particularly her father. She enjoyed taking walks, outings, and her work - as an opportunity to make money and because she liked her supervisor. She participated very little in organized groups or clubs while at Los Lunas.

Each year Dixie was interviewed she expressed her desire to return to Los Lunas. However, as each year passed, her urgency to return diminished. The interviewer reported that during the last contact Dixie expressed the idea of returning as though rehearsing a script. When reminded that no one lived there she dropped the issue.

In the five community visits, Dixie reported two occasions in which she felt unsafe. The first involved the instability she experienced in moving frequently - three times in less than one year. The second disruption came when she alleged that a male staff person had sexually molested

her. Conversely, factors that appear to have assisted her progress were a consistent relationship with caring staff and living in the same home for the past three years.

Consistency of care and provision of a "safe" environment have been key to Dixie's increased emotional stability.

Dixie has had multiple health and behavior problems - asthma, regurgitation, excessive weight and aggression. All of these have dissipated or disappeared during the time she has remained in one home with consistent staffing. A strong indicator of Dixie's increased emotional stability came when she allowed staff to hang a mirror in the house. Prior to this her strong desire to have the house free of all mirrors was respected.

Dixie's access to activities has increased the longer she has lived in the community. It appeared to take time for Dixie and the staff to learn what interested her. Our field researcher noted that Dixie appeared mesmerized by the trees blowing in the wind (a frequent activity), perhaps a reminder of all the trees at Los Lunas. This, and her early response to what she liked to do with friends - "look at birds, go to the mountains or the country" - suggest a desire for a less hectic environment than city activities around a lot of people. She continues to avoid organized activities or community events. At times her access to long day trips away from the city has been curtailed by the agency's limited gasoline budget.

Dixie's contacts with her family have diminished over the last five years. Exactly why is uncertain. However, staff report that Dixie continues to argue with her father about the same issues. She seems to continue to blame him for having to move from Los Lunas even though she has largely dropped this discussion with others. Dixie prefers her social contacts to be with staff on a one-to-one basis. She has recently been relating more to one of her housemates with whom she has lived for three years. She seems to feel safest with him when she can boss him around!

Her day program in the community remains an unfulfilling activity.

Dixie liked her work environment at Los Lunas and hasn't liked work since. Her incidents of aggressive behavior are mostly at work with co-workers. The one aspect of work she has consistently liked is when her work group goes on outings.

Dixie appears to be a homebody with little interest in enlarging her circle of friends or increasing her activities in the community. She appears to enjoy her home, while the memory of good times at Los Lunas is fading into the background. Good relationships with staff and their provision of access to her favorite activity - getting out of town to serene places - are essential to her happiness. Changes in her favorite staff will likely always present a major challenge.

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'Danny'

Danny is a 31-year-old man who is hearing impaired. He has lived in various institutions a good part of his life -the School for the Deaf and Fort Stanton Hospital. He has a history of severe physical and sexual abuse, from which he suffers posttraumatic stress syndrome. Dealing

Danny has often resorted to physical aggression to cope with everyday life, though this has lessened over time.

with day to day life is challenging for him, and Danny has often resorted to property destruction or physical aggression to cope. Although he learned sign language at the School for the Deaf he uses it rarely. He also avoids using a TTY as he doesn't want to appear disabled.

At each visit a sign language interpreter accompanied our interviewer. Danny would respond verbally to her signs and would occasionally use some signing. Our interpreter noted that Danny had been trained in American Sign Language. She observed that when staff members used signing they would use English Sign Language. Only one staff member on one visit was observed using ASL. Danny pointed her out as someone he liked because she used sign.

Danny left Ft. Stanton in November 1993 and moved again two months later. The frequency of aggressive behavior was four to five times a week at first. His aggressive behavior was mostly focused on property destruction and self-abuse, with some incidents of striking staff members. Within the first eight months of his living in the community this behavior had dropped to once or twice a week.

At our first interview (T1), Danny stated he liked living in his house a lot, because it was a home and not an institution. He and the staff listed a number of activities he enjoyed, one being painting. He had a very large canvas - a work in progress - on his living room wall. Danny said that he liked to socialize, but it was clear that this involved staff only. He prefers to live with only a few people. Danny stated that his friends were the girls in the Playboy magazine. He has a large drawer of Playboy magazines and several posters of partially clothed women on his walls. The staff confirmed our interviewer's perception that he is extremely sexually preoccupied.

His difficulties in socializing with peers and his preoccupation with sex have been problematic

At T1, Danny had a job, but was ambivalent about it, stating he liked the people but that it was the wrong job for him. Contact with his mother was by phone; however, she hoped to visit him. Danny participated fully in this first interview.

At T2, Danny had moved to a new house. All of the walls were carpeted with a tasteful design. His bedroom window glass had been removed and replaced with Plexiglas. (Danny was aware the other windows were glass and by T₃ had broken them all!) During both the T2 and T₃ interviews, Danny stated that he didn't much like living in this house. He only minimally participated, was heavily sedated, and communicated considerable fear about fire and staff disrespecting his boundaries. (Staff reported symptoms of Tardis Syskenesia at T₃.) He was not working during this two-year period and his leisure activities were minimal. He had only infrequent contact with his mother.

He continued to be sexually preoccupied and grew increasingly overweight. He claimed to be bored but was also afraid to go out except for car rides. His activities consisted of TV, magazines, sleeping and eating. At the time of the T2 interview he was sleeping 11 hours a night and then 3-4 hours a day. His aggressive episodes of property destruction would cycle every 3 to 4 weeks and last for about 10 days. By T₃, this had decreased.

Danny's life in the community reached a low point during Year 2, due in part to a series of unfortunate events involving residential staff.

During the T₃ interview, Danny described some distressing events regarding staff. One had used his voluntary "safe room" as a locale for seclusion punishment. This staff intervention weakened Danny's concept of having a safe place to retreat to. This staff member had been transferred to another house, but Danny feared he would return. An even more damaging event occurred when two staff members who were apparently dating one another left a burning ember from a cigarette on the mattress in the safe room. When Danny awoke in the night he saw smoke coming from under the door and alerted the night staff. When the door to the safe room was opened, the mattress burst into flames. (The fire was extinguished with minimal physical damage to the carpet.) The period through T₃ was one of considerable fear for Danny - fear of fire, of staff members, and of the destruction of his own property.

During Year 3, his life improved, but "his world was small and his fear still large." Work in the community was "not an option " because of his aggressiveness.

At T₄, Danny was much more alert and actively participated in the interview. He had a housemate he got along with, but his world of activities was still small and his fear still large. He had begun to engage in some new activities, building models and a doghouse. He said that he liked his home "a lot" and noted that he had freedom to do what he wanted. Phone contact with his mother increased. Because of his aggressive behavior, work in the community was not an option. He reported that one staff member had slapped him. We observed and confirmed that staff did not use sign language with him but rather spoke loudly to communicate. Danny's aggressive behavior continued to lessen.

The T₅ interview visit continued to show some slow progress. Danny reported liking his home "some," specifically his freedom. His activity level increased, with more activities outside the house, including picnics, fishing, van rides and building things with Legos. He listed more staff as his friends.

Various fears continue to haunt Danny - the neighbors, being around people on the street, his own sexual impulses. Sexual matters continue to be a big concern. He expressed a deep desire to have a girlfriend. Shortly after the interviewer arrived, he asked, "How are your private parts?" He was clearly trying to present himself appropriately, but has a lot of trouble with impulse control.

Danny's continued adjustment to community life will depend on resolution of his mental health issues.

A successful adjustment to the community will take more time for Danny. He requires the expertise of talented and physically strong staff persons. Successful treatment of his mental health issues is paramount for his full integration into the community.